

Health and Social Care Committee: Supporting People with Long Term Conditions

Consultation response from the Royal College of Paediatrics and Child Health (RCPCH)

May 2023

About the RCPCH and our response

The RCPCH works to transform child health through knowledge, innovation and expertise. We have over 500 members in Wales, 14,000 across the UK and over 17,000 worldwide. The RCPCH is responsible for training and examining paediatricians. We also advocate on behalf of members, represent their views and draw upon their expertise to inform policy development and the maintenance of professional standards.

We agree with the Committee that issues around chronic conditions are wide ranging and complex. With this in mind, we will seek to identify a small number of key considerations that we hope will help inform the Committee's thinking and understanding of the issues around long term conditions in children and young people, rather than take an in-depth look at specific conditions and care pathways. We'll align these as far as possible to the broad areas identified by the Committee on the [consultation page](#).

We would be pleased to elaborate on this response in an oral evidence session, should the Committee have further questions or wish to hear more about supporting children and young people with long term conditions. For further information please contact Lisa Roberts, Policy and Public Affairs Officer (Wales) at the RCPCH at lisa.roberts@rcpch.ac.uk.

Key considerations

Prioritising children and young people is essential to ensure that services can meet future demand.

In years gone by, the majority of deaths in children were in those acutely unwell from infectious disease with no underlying morbidities. The number of children with a single long-term health condition such as asthma, diabetes, inflammatory bowel disease, eczema and epilepsy has increased significantly in more recent years. Now, between 60% and 70% of children who die in the UK have a long term condition¹.

There is therefore a strong case for prioritising children and young people in formulating policy, resourcing and services around long term illness², including the long term implications for health services. Healthy children are more likely to become healthy adults. Poor health outcomes in childhood are likely to progress into adulthood. If we take mental health as an example, the Mental Health Foundation report that 50% of mental health problems are established by age 14 and 75% by age 24³. Meanwhile, Young Minds note that One-third of mental health problems in adulthood are directly connected to an adverse childhood experience and that adults who experienced four or more adversities in their childhood are four times more likely to have low levels of mental wellbeing and life satisfaction⁴.

The Welsh Government recognises the strength of the case for prioritising children and young people and have set this out in at least two key documents. It's long term strategy for health and social care, A Healthier Wales, noted the case for prioritising children and young people, drawing on evidence from an earlier Parliamentary Review⁵. The Welsh Government's programme for transforming and modernising planned care and reducing waiting lists in Wales builds on this, noting that "waiting times for children must be considered differently to waiting times for an adult, as the illness will represent a higher proportion of a child's whole life and potentially have permanent long term impact on growth and development"⁶. The document also

¹ Royal College of Paediatrics and Child Health (2020), 'Child with Single Long Term Condition' in *Paediatrics 2020: Forecasting the Future*. Available at: <https://paediatrics2040.rcpch.ac.uk/our-evidence/models-of-care/future/#page-section-9>. Accessed May 2023.

² For a discussion of some aspects of this case see, for example, Lignou S, Wolfe I Healthcare prioritisation and inequitable inequalities: why a child health perspective should be incorporated into the current NHS guidance. *Archives of Disease in Childhood* Published Online First: 19 May 2023. Available at: <https://adc.bmj.com/content/early/2023/05/18/archdischild-2023-325634>. Accessed May 2023.

³ Mental Health Foundation *Children and Young People Statistics*, available at: <https://www.mentalhealth.org.uk/explore-mental-health/statistics/children-young-people-statistics#:~:text=50%25%20of%20mental%20health%20problems,and%2075%25%20by%20age%2024>. Accessed May 2023.

⁴ Young Minds *Mental Health Statistics*, available at <https://www.youngminds.org.uk/about-us/media-centre/mental-health-statistics/>. Accessed May 2023.

⁵ See Welsh Government (2018) A Healthier Wales, p18. Available at: <https://www.gov.wales/healthier-wales-long-term-plan-health-and-social-care>. Accessed May 2023.

⁶ Welsh Government *Our programme for transforming and modernising planned care and reducing waiting lists in Wales* (2022), p22. Available at: <https://www.gov.wales/sites/default/files/publications/2022-04/our->

makes reference to prioritising or recognising particular needs of children and young people in terms of dentistry⁷, mental health⁸, elective care⁹ and diagnosis¹⁰. Given the impact that living with a chronic illness during childhood has on school attendance, health in adulthood and on a person's lifetime opportunities, we strongly believe that prioritising children and young people is key to ensuring that services can meet future demand.

We would encourage the Committee to consider hearing directly from children and families living with long term conditions and to look at resources we have produced with our engagement network, called [RCPCH &Us](#). This includes, as an example, specific work with children and young people on their experiences of epilepsy care¹¹.

Underpinning any commitment to prioritising children and young people's health must be a properly resourced child health workforce with the appropriate capacity to manage demand and ensure timely access to paediatric services. Over the past two years we have seen significant increases in waiting lists to access general paediatric services and in particular in waits of over 36 weeks¹². We would like to see delivery and implementation of existing workforce plans in Wales, which must be properly resourced and funded; and enable proactive planning and modelling based on robust workforce data, in line with commitments made in '[Healthier Wales: Our Workforce Strategy for Health and Social Care](#)' and '[Our Programme for Transforming and Modernising Planned Care and Reducing Waiting Lists in Wales](#)'.

Finally, we must also ensure that services work together. This is not only across education and social care but also between paediatric and adult care to ensure the needs of adolescents and young adults are met. This population consistently lags behind in improvements in morbidity and mortality and attracts the least funding yet is the time when health related knowledge and behaviours are typically set. It is essential that services for this population acknowledge key neurodevelopmental issues and reduced life experience and are in line with principles set out by the Welsh Government¹³. We elaborate on this point and its importance in terms of managing chronic conditions in Paediatrics 2040:

[programme-for-transforming--and-modernising-planned-care-and-reducing-waiting-lists-in-wales.pdf](#). Accessed May 2023.

⁷ Welsh Government (2022), p9.

⁸ Welsh Government (2022), p10.

⁹ Welsh Government (2022), p23

¹⁰ Welsh Government (2022), p2.

¹¹ Royal College of Paediatrics and Child Health (2018), *Epilepsy12 &Us - voices from the RCPCH &Us network*. Available at: <https://www.rcpch.ac.uk/resources/epilepsy12-us-voices-rcpch-us-network>. Accessed May 2023.

¹² See Stats Wales, *Patient pathways waiting to start treatment by month, grouped weeks and treatment function, January 2021 onwards*. Available at: <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Referral-to-Treatment/patientpathwayswaitingtostarttreatment-by-month-groupedweeks-treatmentfunction>. Accessed May 2023.

¹³ See Welsh Government (2022), *Transition and handover from children's to adult health services*. Available at: <https://www.gov.wales/transition-and-handover-childrens-adult-health-services>. Accessed May 2023.

“Getting health services right for adolescents is of critical importance, as it is during this period that many long-term health conditions emerge, and associated behaviours can have most impact. Offering developmentally appropriate care with the ability to adapt to changing biopsychosocial profiles, and addressing physical, sexual, social and mental health needs in consultations, will be important. Dedicated young people’s clinics, specific ward areas, the presence of youth workers and a multidisciplinary approach are all considerations, as well as integration with primary care and adult physicians. The RCP has a toolkit which sets out some broad categories and reminds us to consider information sharing, professional responsibilities and confidentiality.¹⁴”

Inequalities and the impact of the cost of living crisis

Our position statement on [Child health inequalities driven by child poverty in the UK](#) and the [Mind the Gap](#) report produced by the NHS Confederation and a number of Medical Royal Colleges and third sector groups in Wales, clearly set out the evidence on links between poverty, inequalities and poor health outcomes. The former includes specific consideration of long term conditions, noting that:

- Children living in poverty are significantly more likely to suffer from acute and long-term illness. They are significantly more likely to require hospital admission and were 72% more likely than other children to be diagnosed with a long-term illness.
- In Wales, the gap between obesity prevalence in the most and least income deprived quintiles has increased from 5.9% in 2017/18 to 6.9% in 2018/19.
- Children living in poverty are more likely to be at risk of tooth decay, in prevalence and severity. In Wales, 42.2% of five-year olds in the most income deprived areas have tooth decay, compared to just 22.3% in the least income deprived areas.
- Children living in the poorest 20% of households in the UK are four times more likely to develop a mental disorder as those from the wealthiest 20%.¹⁵

Another example would be asthma. Our State of Child Health report notes that:

- **Asthma is the most common long term condition among children and young people in the UK**, with 1.1 million children currently receiving asthma treatment. It continues to be among the top 10 causes of emergency hospital admission for children and young people in the UK.
- **The UK has among the highest mortality rates in Europe** for children and young people with the underlying cause of asthma.

¹⁴ Royal College of Paediatrics and Child Health (2020), *Paediatrics 2040: Forecasting the Future*. Available at: <https://paediatrics2040.rcpch.ac.uk/our-evidence/models-of-care/future/>. Accessed May 2023.

¹⁵ Royal College of Paediatrics and Child Health (RCPCH), 2022. *Child health inequalities driven by child poverty in the UK - position statement*. Available at: <https://www.rcpch.ac.uk/resources/child-health-inequalities-position-statement>. Accessed May 2023.

- **Emergency admissions, and deaths, related to asthma are largely preventable** with improved management and early intervention.
- **Emergency admissions for asthma are strongly associated with deprivation.** Children and young people living in deprived areas are more likely to be exposed to higher levels of tobacco smoke and environmental pollution, which may contribute to this. If emergency admission rates for all children and young people were at the levels experienced by the least deprived group, this could save the NHS £8.5 million per year in England alone.¹⁶

Although this final point looks at England specifically, the principle is relevant in Wales.

We therefore welcome the announcement that there will be a refreshed and updated child poverty strategy for Wales, which we hope will be prioritised and expedited; and we would encourage the Welsh Government to consider child health outcomes and child health inequalities as part of that work. The strategy should provide national targets to reduce child poverty rates, with clear accountability across Government. We would also encourage the Welsh Government to review and expand the [Children and Young People Plan](#) so that future iterations form a comprehensive cross-departmental child health and wellbeing strategy that will address health inequalities and the impact of child poverty; and outline the role each department has in contributing to solutions.

Among the many areas in which long term conditions and child health inequalities intersect is in school attendance. With this in mind, we Welcome the Welsh Government's [Whole School Approach](#) to mental health and the Healthy Schools scheme delivered by Public Health Wales. We urge the Welsh Government to ensure these programmes are adequately resourced and delivered at pace with robust evaluation to capture and roll out learning. A wider 'whole school approach' to health could incorporate physical as well as mental health and we note that organisations working with or on behalf of children and young people with diabetes¹⁷, arthritis¹⁸, Coeliac disease¹⁹, epilepsy²⁰ and other conditions as well as the *Health Conditions in School Alliance* have produced resources that may be of use to education professionals in considering how to support learners with chronic conditions.

¹⁶ Royal College of Paediatrics and Child Health *State of Child Health* available at:

<https://stateofchildhealth.rcpch.ac.uk/evidence/long-term-conditions/asthma/>. Accessed May 2023.

¹⁷ See, for example, Diabetes UK, *Diabetes in School*. Available at: <https://www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools>.

¹⁸ See, for example, Versus Arthritis, *Supporting a young person with arthritis at school*. Available at: <https://www.versusarthritis.org/media/24208/supporting-a-young-person-information-booklet-oct2021.pdf>

¹⁹ See, for example, Coeliac UK, *Coeliac disease at school*. Available at: <https://www.coeliac.org.uk/information-and-support/living-gluten-free/kids-teens-and-young-adults/coeliac-disease-at-school/>. Accessed May 2023.

²⁰ See, for example, Young Epilepsy, *Attendance*. Available at: <https://www.youngpilepsy.org.uk/guide-schools-epilepsys-impact-learning/guide-schools-attendance>; and *Exams and Coursework*. Available at: <https://www.youngpilepsy.org.uk/guide-schools-epilepsys-impact-learning/guide-schools-exams-coursework>

Action to improve prevention and early intervention.

Action to prevent children and young people from developing chronic or long term conditions is absolutely vital if we are to reduce the numbers of children and young people being ill, missing school or requiring hospital treatment – and if we are to safeguard services in the future.

We have welcomed the Welsh Government's [Healthy Weight Healthy Wales](#) programme, which must be delivered in full and at pace, given the extremely concerning data on childhood obesity and the inequalities underpinning those numbers revealed by the [Child Measurement Programme for Wales](#). Healthy Weight Healthy Wales includes a commitment to expanding that programme²¹ so that we have data points other than at reception age and are better able to understand children and young people's weight throughout their school careers. This work must be delivered with urgency. We have also called for full and swift implementation of the policy and legislative package around the healthy food environment consulted upon by the Welsh Government last year as part of its HWHW commitments²².

HWHW also includes a range of commitments and interventions to increase physical activity and reduce sedentary behaviour and lifestyles in children and young people, which we welcome both as a measure to reduce childhood obesity and to improve children's health more broadly by supporting a healthier lifestyle which can contribute to preventing long term disease. The Welsh Government consulted last year on a new framework for social prescribing²³ in Wales and we hope that when the updated framework is published, that it will have a far greater focus on children and young people in general and in particular greater consideration as to how social prescribing can interact with community sport and leisure facilities and youth clubs to encourage physical activity; as well as interact with other relevant Welsh Government initiatives, legislation and programmes such as the ALN framework, the healthy schools programme and the Whole School Approach. The social prescribing framework could also be helpful in developing self-management tools specifically for children and young people living with long term illness: experience from members suggests that self-management support can often be adult-focused.

We have also been supportive of the Welsh Government's commitments around tobacco control and its strategy, [A Smoke Free Wales](#). In particular we have welcomed the ambition for Wales to be smoke-free Wales by 2030, the commitment

²¹ See Welsh Government (2022) *Healthy Weight Healthy Wales Moving Ahead in 2022- 2024*, National Priority Area 7. Available at: https://www.gov.wales/sites/default/files/publications/2022-03/healthy-weight-healthy-wales-2022-to-2024-delivery-plan_0.pdf. Accessed May 2023.

²² See Royal College of Paediatrics and Child Health (2022) *Healthy Food Environment (Wales) – consultation response*. Available at: <https://www.rcpch.ac.uk/resources/healthy-food-environment-wales-consultation-response>. Accessed May 2023.

²³ See Welsh Government, *Developing a national framework for social prescribing*. Available at: <https://www.gov.wales/developing-national-framework-social-prescribing>. Accessed May 2023.

to taking further steps to protect people from the harms of second-hand smoke and the focus on children and young people²⁴.

We have previously noted the importance of prevention and early intervention around mental health and neurodiversity and the need to ensure comprehensive rollout of programmes such as the NYTH/NEST approach and the Whole School Approach.

Finally, we have also welcomed a Welsh Government White Paper on legislation for better air quality in Wales.

Taken together, these strategies and policies could have a significant impact on preventing long term illness in children and young people. We are also pleased to see that preventative initiatives in Wales take a whole family approach (for example, we are aware that Public Health Wales are piloting children and families projects as part of Healthy Weight Healthy Wales; and understand that work around preventing Adverse Childhood Experiences or ACEs has a focus on the wider family as well as the individual child). Taking a whole family approach to supporting healthy choices and preventing generational cycles of behaviours detrimental to health could be beneficial in a range of other preventative and self-management approaches to long term illness in children, such as managing chronic pain and fatigue.

²⁴ See Royal College of Paediatrics and Child Health (2022), *Tobacco control strategy and delivery plan (Wales) consultation response*. Available at: <https://www.rcpch.ac.uk/resources/tobacco-control-strategy-delivery-plan-wales-consultation-response>. Accessed May 2023.